Complementary and Alternative Medicine for Duchenne and Becker Muscular Dystrophies: Characteristics of Users and Caregivers

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Abstract

BACKGROUND—Complementary and alternative medicine is frequently used in the management of chronic pediatric diseases, but little is known about its use by those with Duchenne or Becker muscular dystrophy.

METHODS—Complementary and alternative medicine use by male patients with Duchenne or Becker muscular dystrophy and associations with characteristics of male patients and their caregivers were examined through interviews with 362 primary caregivers identified from the Muscular Dystrophy Surveillance, Tracking, and Research Network.

RESULTS—Overall, 272 of the 362 (75.1%) primary caregivers reported that they had used any complementary and alternative medicine for the oldest Muscular Dystrophy Surveillance, Tracking, and Research Network male in their family. The most commonly reported therapies were from the mind-body medicine domain (61.0%) followed by those from the biologically based practice (39.2%), manipulative and body-based practice (29.3%), and whole medical system (6.9%) domains. Aquatherapy, prayer and/or blessing, special diet, and massage were the most frequently used therapies. Compared with nonusers, male patients who used any therapy were more likely to have an early onset of symptoms and use a wheel chair; their caregivers were more likely to be non-Hispanic white. Among domains, associations were observed with caregiver education and family income (mind-body medicines [excluding prayer and/or blessing only] and whole medical systems) and Muscular Dystrophy Surveillance, Tracking, and Research Network

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site (biologically based practices and mind-body medicines [excluding prayer and/or blessing only]).

CONCLUSIONS—Complementary and alternative medicine use was common in the management of Duchenne and Becker muscular dystrophies among Muscular Dystrophy Surveillance, Tracking, and Research Network males. This widespread use suggests further study to evaluate the efficacy of integrating complementary and alternative medicine into treatment regimens for Duchenne and Becker muscular dystrophies.

Keywords

Becker muscular dystrophy; complementary therapies; Duchenne muscular dystrophy; neuromuscular diseases

Introduction

Complementary and alternative medicine (CAM) has traditionally been described as medical practices and use of therapies not regarded as conventional medicine. Currently the National Center for Complementary and Alternative Medicine endorses the term "complementary health approaches" to describe those medical practices and products used to manage disease.[1] The evolving views can complicate studies of CAM use because of changes in definitions and designations of certain therapies as CAM. Historically, estimates of CAM use in different countries have ranged from 9% to 73%.[2] A recent US survey estimated that one in nine children used some form of CAM,[3] and other US studies observed CAM use was higher among children with chronic conditions.[4-14] In addition, disease prognosis and severity,[4,5] as well as caregiver characteristics,[11-14] have been found to influence CAM use in children.

Although some CAM therapies have been increasingly used in pediatric populations, little data exist regarding CAM use among those affected with Duchenne or Becker muscular dystrophy. Samdup et al.[15] conducted a clinic-based study among Canadian children with chronic medical conditions and observed three of 15 (20%) with Duchenne muscular dystrophy used CAM. A study using data from a population-based cohort of male patients with Duchenne or Becker muscular dystrophy identified by the Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STAR*net*) estimated that 80% of families used CAM for their children.[16] This analysis also evaluated the impact of care-giver characteristics on CAM use and observed caregivers who reported use of whole medical system therapies for their childrenwere more likely to have college education and a higher family income.[16]

With clinical trials investigating the effectiveness of novel therapies for Duchenne and Becker muscular dystrophies increasingly being implemented,[17,18] information related to patient characteristics and CAM use is important to monitor interactions between CAM and therapies being tested. In recent years, the MD STAR*net* has expanded the number of participating sites and correspondingly, the available data from this well-described cohort. Using data from this expanded population, the objectives of the present study were to estimate CAM use by the oldest affected male in each MD STAR*net* family and to

investigate associations between CAM use and characteristics of these male patients and their primary caregivers.

Methods

The MD STAR*net* is a multisite, population-based study initiated in 2002 to identify individuals diagnosed with Duchenne or Becker muscular dystrophy born on or after January 1, 1982 through December 31, 2011 and residing in Arizona, Colorado, Iowa, or 12 counties in western New York State. The MD STAR*net* was expanded to Georgia in 2005 and Hawaii in 2008. The surveillance methodology developed for the MD STAR*net* has been described elsewhere.[19] A committee of neuromuscular clinicians experienced in treating patients with Duchenne or Becker muscular dystrophy reviewed medical record data collected by trained abstractors and assigned a case status (definite, probable, possible, asymptomatic, or affected female) to each individual as detailed elsewhere.[20]

Interview data collection

Primary caregivers of MD STAR*net* males with definite or probable case status were invited to participate in a structured interview developed by MD STAR*net* investigators to examine socioeconomic and acculturation factors, social support, early development, clinical outcomes, and use of CAM, medical services, and assistive devices. A systematic recruitment protocol was used to obtain caregiver consent to conduct the interview. The interview protocol was approved by the institutional review board at each MD STAR*net* site.

Interview items for CAM use were based on previous studies.[21,22] Primary caregivers were asked if the MD STAR*net* male had ever used a CAM therapy read from a prespecified list. If the therapy was used, caregivers were asked if it was recommended by a health care provider. Caregivers were also asked to report use of any additional CAM therapies not listed and if these therapies were recommended by a health care provider. Because a major source of CAM information is obtained from friends and family members,[23] CAM use by multiple MD STAR*net* males from the same family is likely to be correlated; thus, only the data from the oldest affected male in each family were included in the current analysis. Data from Hawaii were excluded because there were only two caregiver participants from that state.

Statistical analysis

CAM use was examined by selected characteristics of MD STAR*net* males and their primary caregivers. Characteristics of males examined were disease phenotype, use of wheel chairs or noninvasive positive pressure ventilation devices, vital status, and number of years since disease diagnosis. Disease phenotype was based on the age of onset of symptoms. If symptoms occurred before the sixth birthday, disease was classified as early onset, otherwise it was classified as late onset.[16] The number of years since disease diagnosis was calculated as the difference between age at interview and age at diagnosis. If the male was deceased at the time of interview, the age at death was used instead of the age at interview. Caregiver characteristics examined were age at interview, race and ethnicity, marital status

(if the caregiver was the biological parent), education, family income, and MD STAR*net* site.

SAS 9.3 (SAS Institute, Cary, NC) was used for statistical analysis. To allow comparisons with a previous study of CAM use in the MD STAR*net* population,[16] CAM therapies reported by the caregiver were classified into the following domains: biologically based practices (herbs, special diet, megavitamins, and glycoproteins); manipulative and body-based practices (massage, chiropractic manipulation, and osteopathic manipulation); mind-body medicine (aquatherapy, hippotherapy, self-hypnosis, prayer and/or blessings, and companion animals); whole medical systems (acupuncture and homeopathy); and other. Additional analyses were conducted for special diet, massage, and aquatherapy individually. These were the most commonly reported CAM therapies used in the previous MD STAR*net* analysis.[16] Because of the debate of whether prayer and/or blessing is recognized as a CAM therapy,[3,6] separate analyses were performed for the mind-body medicine domain with and without caregivers who only reported use of prayer and/or blessing in that domain.

For users and nonusers in each CAM domain, the chi-square test or Fisher exact test was used to compare categorical characteristics of MD STAR*net* males and primary caregivers. The *t* test was used to compare continuous variables. For each test, $P < 0.05$ was considered to be statistically significant. Because CAM therapies reported by a caregiver could be from multiple domains, the observations across domains did not necessarily represent independent caregivers. Given that this is a descriptive analysis, adjustment for multiple comparisons was not made. Additionally, there is controversy in whether to adjust for multiple comparisons in epidemiologic studies, and in which methods to apply.[24-26]

Results

Overall, 362 primary caregivers completed the interview. Using the American Association for Public Opinion Research calculator,[27] the response rate was 53% and the cooperation rate was 66%. Surveillance data were used to compare characteristics of caregiver participants and the oldest MD STAR*net* males with those of all eligible caregivers and oldest males. A statistically significant difference was observed for MD STAR*net* site ($P = 0.02$), but not for vital status, year of birth, or parental race and ethnicity and education ($P > 0.05$) (data not revealed).

CAM use

Of the 362 participants, 272 (75%) reported any CAM use by their oldest MD STAR*net* male. The total number of individual CAM therapies reported by caregivers ranged from 1 to 12; 87 (32%) reported one therapy, 77 (28%) reported two therapies, 44 (16%) reported three therapies, and 64 (24%) reported four or more CAM therapies (data not revealed). Aquatherapy, prayer and/or blessing, special diet, and massage were the most frequently used CAM therapies (Table 1). When examined by domains, therapies in the mind-body medicine domain were the most commonly reported by primary caregivers (61.0%), followed by those in the biologically based practice (39.2%), manipulative and body-based practice (29.3%), and whole medical system domains (6.9%). Also, 32 caregivers (8.8%) reported use of other CAM therapies, which included equine therapy, Haelan therapy, yoga,

reiki, fire cupping, gwa sha, Qi gong, and electrotherapy, as well as coenzyme Q10, creatine, and melatonin supplement use (data not revealed). Overall, 170 (47%) male patients had used at least one CAM therapy recommended by a health care provider (data not revealed); special diet and aquatherapy were the most frequently recommended therapies.

Associations between CAM use and characteristics of MD STARnet *males and primary caregivers*

Compared with nonusers, MD STAR*net* males who used any CAM were more likely to be classified with the early-onset phenotype ($P < 0.05$) and using a wheel chair ($P < 0.05$); no statistically significant associations were observed for other characteristics (Table 2). Similar results were observed when CAM use was examined by individual domains, except for the association between wheel chair use and users of manipulative and body-based practice therapies ($P = 0.059$, data not revealed), and the associations between disease phenotype and wheel chair use among users of whole medical system therapies ($P > 0.05$). Among the most frequently reported CAM therapies, massage users were more likely to use a wheel chair ($P < 0.01$), and a larger proportion of aquatherapy users had the early-onset phenotype ($P < 0.01$) or used a wheel chair ($P < 0.01$); no significant associations were observed between use of a special diet and any male characteristic examined.

A statistically significant association was observed between any CAM use and primary caregiver race and ethnicity; caregivers of CAM users were more likely to be non-Hispanic white than caregivers of nonusers ($P < 0.05$) (Table 3). Similar associations were observed for the domains of biologically based practices, mind-body medicine (with or without prayer and/or blessing), and whole medical systems ($P < 0.05$). Comparison of users and nonusers by individual CAM domains revealed that caregivers of MD STAR*net* males who used biologically based practice therapies were more likely to reside in Arizona ($P < 0.05$); those caregivers of male patients who used mind-body medicine therapies (excluding prayer and/or blessing only) had higher education levels, higher family income, or were more likely to reside in New York State ($P < 0.05$); and those caregivers of male patients who used whole medical system therapies were more likely to have higher education and higher family income ($P < 0.01$). Also, a larger percentage of caregivers of male patients who used special diet resided in Arizona ($P < 0.01$); caregivers of male patients who used aquatherapy were more likely to be non-Hispanic white ($P < 0.05$), reside in New York State ($P < 0.01$), and have higher family incomes ($P < 0.05$). No significant associations were observed between caregiver characteristics and massage therapy use among MD STAR*net* males.

Discussion

The present study estimated that 75% of MD STAR*net* primary caregivers reported CAM use by their oldest affected male. This was greater than previous reports of 20% among children with Duchenne muscular dystrophy[15] and 44% among children with neurological disorders.[28] These differences could be explained in part by whether current use or lifetime use was investigated, whether the study was clinic-based or population-based, and the number and type of CAM therapies examined.

The present study also observed that 47% of MD STAR*net* males had used at least one CAM therapy recommended by a health care provider. Such data were not collected in previous studies of children with Duchenne muscular dystrophy[15] or neurological disorders,[28] although a survey conducted in a large US metropolitan children's hospital reported that 67% of pediatricians recommended CAM to their patients.[10] This difference may be due in part to the variability in practice approaches across MD STAR*net* sites compared with potentially less variable approaches within one children's hospital.

Aquatherapy was the most frequently recommended CAM in the present study. This may be due in part to possible beneficial effects of such therapy on motor function in children[29] and the movement toward its acceptance as a conventional therapy.[30] Special diet (e.g., low-calorie or low-fat diet) was another commonly recommended CAM therapy for MD STAR*net* males. The use of aquatherapy and special diet has been recommended as part of standard clinical management of Duchenne muscular dystrophy.[31] As the most commonly recommended CAM therapies in the MD STAR*net* population, the efficacy of aquatherapy and special diet in modifying symptom severity and rate of disease progression requires further investigation.

Consistent with studies that reported associations between CAM use and disease severity,[5,15,32] the present study found MD STAR*net* males with early onset of symptoms and who used a wheel chair were more likely to use CAM. Some studies suggested that parental demographic characteristics, such as age,[12] race and ethnicity,[13,23] education,[11,15,23,32] and family income,[5] influence CAM use among pediatric patients, but these findings were not supported in other studies.[9,28,33] The present study did suggest that associations with caregiver characteristics were domain specific. For example, caregiver education and family income were not significantly associated with any CAM use; however, caregivers with a higher education and higher family income were more likely to report use of whole medical system therapies and mind-body medicine (excluding prayer and/or blessing) therapies by MD STAR*net* males. The cost of these latter therapies and the differences in coverage of such costs by third-party payers may partly explain the observed associations. Differences in CAM use by MD STAR*net* site were significant for biologically based practice and mind-body medicine (excluding prayer and/or blessing) therapies. Similarities in provider recommendations within sites may have contributed to these associations.

Findings from this descriptive study should be interpreted cautiously. With a response rate of 53%, findings of CAM use may not generalize to the total MD STAR*net* population, although selected characteristics of primary care-givers and oldest affected males among the participants were similar to those among all eligible caregivers and oldest affected males. Primary caregiver reports of life-time CAM use could be subject to underreporting; however, the number of years since disease diagnosis and time at interview was similar between CAM users and nonusers. Caregivers might also have underreported dietary supplements other than herbs, vitamins, or minerals, because such response choices were not provided in the interview. Moreover, a parent's personal experience with CAM has been reported to be significantly associated with CAM use in their children.[7,11,14,28,32] In the current study, data were not available to evaluate the impact of parental personal experience

with CAM. Additionally, the reported use of certain therapies, such as osteopathic manipulation and acupuncture, was low, which could reflect the lack of specialists who provide these treatments. Without knowing the availability of specialists in the surveillance areas, it is difficult to evaluate why use of certain therapies is so low. Despite these limitations, the strengths of this study are the use of a cohort of males identified by systematic, population-based medical record review,[19] detailed case definitions assigned by neuromuscular clinicians,[20] and the large sample of primary caregivers.

It is important to note that the designation of a certain therapy as CAM is evolving over time, as is the approach to classifying types of CAM into broader domains. Currently, the NCCAM describes CAM therapies as "complementary health approaches" of which they identify two subgroups, "natural products," and "mind and body practices".[1] Although the present study classified CAM therapies into domains previously recognized by the NCCAM, the constructed domains are consistent with current NCCAM groupings, while providing greater specificity of therapy types. Retaining this greater specificity seemed an appropriate approach considering emerging views of certain therapies as conventional medicine.

In summary, the present study observed high estimates of CAM use in disease management among MD STAR*net* males. Further studies are recommended to evaluate efficacy of CAM therapies being integrated into conventional treatment regimens.

Acknowledgments

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TABLE 1

Reported Use of Complementary and Alternative Medicine in Male Patients With Duchenne or Becker Muscular Dystrophy, Muscular Dystrophy Surveillance, Tracking, and Research Network

CAM Domain and/or Therapy	Use n (%)[*]	Provider Recommended n (%)[†]
Biologically based practices[‡]	142 (39.2)	81 (57.0)
Herbs, mouth	61 (16.9)	16 (26.2)
Herbs, skin	25 (6.9)	3 (12.0)
Special diet	78 (21.5)	56 (71.8)
Megavitamins	29 (8.0)	16 (55.2)
Glycoproteins	11 (3.0)	1 (9.1)
Manipulative and body-based[‡]	106 (29.3)	29 (27.4)
Massage	78 (21.5)	29 (37.2)
Chiropractic manipulation	54 (14.9)	6 (11.1)
Osteopathic manipulation	10 (2.8)	2 (20.0)
Mind-body medicine[‡]	221 (61.0)	99 (44.8)
Aquatherapy	136 (37.6)	89 (65.4)
Hippotherapy	48 (13.3)	16 (33.3)
Self-hypnosis	2 (0.6)	0 (0.0)
Prayer and/or blessings	126 (34.8)	2 (1.6)
Companion animals	21 (5.8)	2 (9.5)
Whole medical systems[‡]	25 (6.9)	5 (20.0)
Acupuncture	7 (1.9)	2 (28.6)
Homeopathy	21 (5.8)	4 (19.0)
Other	32 (8.8)	17 (53.1)

Abbreviation:

CAM = Complementary and alternative medicine

[*] Denominator used to calculate the percentage is the number of male patients with Duchenne or Becker muscular dystrophy included in this study (n = 362).

[†] Denominator used to calculate the percentage is the number of users for each specific CAM therapy or domain.

[‡] Total number of users for each CAM domain was less than sum of the number of users for individual CAM therapies within the domain because of the use of more than one CAM therapy.

TABLE 2

Comparison of Selected Characteristics of Male Patients With Duchenne or Becker Muscular Dystrophy by Complementary and Alternative Medicine Use, Muscular Dystrophy Surveillance, Tracking, and Research Network

| Characteristic | Nonusers (n = 90) | Any CAM (n = 272) | CAM Domains | | | | | CAM Therapies | | |
			Biologically Based Practices (n = 142)	Manipulative and Body-Based Practices (n = 106)	Mind-Body Medicine (n = 221)	Mind-Body (Excluding Prayer and/or Blessing Only) (n = 160)	Whole Medical Systems (n = 25)	Special Diet (n = 78)	Massage (n = 78)	Aquatherapy (n = 136)
Disease Phenotype[*]										
Early onset	69 (76.7)	232 (85.6)	123 (87.2)	92 (87.6)	192 (87.3)	143 (89.4)	20 (83.3)	66 (84.6)	67 (85.9)	121 (89.0)
Late onset	21 (23.3)	39 (14.4)	18 (12.8)	13 (12.4)	28 (12.7)	17 (10.6)	4 (16.7)	12 (15.4)	11 (14.1)	15 (11.0)
Number of years since diagnosis	9.4 ± 5.7	9.9 ± 5.7	10.0 ± 5.9	10.0 ± 5.8	10.0 ± 5.6	10.0 ± 5.7	9.7 ± 5.5	10.0 ± 5.8	10.3 ± 5.7	9.9 ± 5.7
Used wheel chair[†]										
Yes	52 (59.8)	201 (73.9)	105 (73.9)	77 (72.6)	169 (76.5)	125 (78.1)	19 (76.0)	56 (71.8)	62 (79.5)	107 (78.7)
No	35 (40.2)	71 (26.1)	37 (26.1)	29 (27.4)	52 (23.5)	35 (21.9)	6 (24.0)	22 (28.2)	16 (20.5)	29 (21.3)
Age first used wheel chair (yr)	9.9 ± 2.9	9.3 ± 2.6	9.1 ± 2.4	9.2 ± 2.4	9.5 ± 2.7	9.6 ± 2.9	9.6 ± 2.2	9.2 ± 2.7	9.4 ± 2.6	9.5 ± 2.9
Used NIPPVD										
Yes	20 (23.0)	70 (25.9)	37 (26.4)	29 (27.6)	60 (27.4)	44 (27.9)	5 (20.0)	22 (28.6)	19 (24.7)	36 (26.9)
No	67 (77.0)	200 (74.1)	103 (73.6)	76 (72.4)	159 (72.6)	114 (72.2)	20 (80.0)	55 (71.4)	58 (75.3)	98 (73.1)
Age first used NIPPVD (yr)	16.1 ± 3.4	15.0 ± 3.3	14.5 ± 3.4	15.5 ± 3.3	14.9 ± 3.2	14.6 ± 3.3	13.8 ± 2.4	14.7 ± 3.7	15.9 ± 3.0	14.4 ± 3.2
Vital status at interview										
Living	79 (87.8)	251 (92.3)	133 (93.7)	97 (91.5)	204 (92.3)	147 (91.9)	24 (96.0)	74 (94.9)	71 (91.0)	124 (91.2)
Deceased	11 (11.2)	21 (7.7)	9 (6.3)	9 (8.5)	17 (7.7)	13 (8.1)	1 (4.0)	4 (5.1)	7 (9.0)	12 (8.8)

Abbreviations:

CAM = Complementary and alternative medicine

NIPPVD = Noninvasive positive pressure ventilation devices

Categorical variables were presented as N (%) and analyzed by the chi-square test or Fisher exact test; continuous variables were presented as mean ± standard deviation and analyzed by the *t* test. Nonusers were the comparison group. Because of missing values, the total for some categories may not match; because of rounding, percentages may not total 100.

*Significant associations between disease phenotype and use of any CAM ($P < 0.05$), biologically based practices ($P < 0.05$), manipulative and body-based practices ($P < 0.05$), mind-body medicine (with or without prayer and/or blessings only) ($P < 0.05$), and aquatherapy ($P < 0.05$).

†Significant associations between wheel chair use and use of any CAM ($P < 0.05$), biologically based practices ($P < 0.05$), mind-body medicine (with or without prayer and/or blessings only) ($P < 0.01$), massage ($P < 0.01$), and aquatherapy ($P < 0.01$).

TABLE 3

Comparison of Selected Characteristics of Primary Caregiver of Male Patients With Duchenne or Becker Muscular Dystrophy by Complementary and Alternative Medicine Use, Muscular Dystrophy Surveillance, Tracking, and Research Network

Primary Caregiver Characteristic	Nonusers (n = 90)	Any CAM (n = 272)	CAM Domains					CAM Therapies		
			Biologically Based Practices (n = 142)	Manipulative and Body-Based Practices (n = 106)	Mind-Body Medicine (n = 221)	Mind-Body (Excluding Prayer and/or Blessing Only) (n = 160)	Whole Medical Systems (n = 25)	Special Diet (n = 78)	Massage (n = 78)	Aquatherapy (n = 136)
Age at interview (yr)										
20-39	27 (35.1)	81 (32.0)	39 (28.5)	33 (33.3)	64 (30.8)	41 (27.2)	4 (16.7)	22 (29.0)	24 (32.9)	37 (28.7)
40-49	40 (52.0)	127 (50.2)	68 (49.6)	50 (50.5)	111 (53.3)	83 (55.0)	13 (54.2)	38 (50.0)	35 (48.0)	67 (51.9)
>50	10 (13.0)	45 (17.8)	30 (21.9)	16 (16.2)	33 (15.9)	27 (17.8)	7 (29.2)	16 (21.0)	14 (19.2)	25 (19.4)
Race and ethnicity*										
Non-Hispanic white	51 (66.2)	200 (79.4)	111 (81.6)	74 (75.5)	167 (80.7)	126 (84.0)	21 (91.3)	60 (80.0)	51 (70.8)	106 (82.8)
Hispanic	15 (19.5)	34 (13.5)	18 (13.2)	17 (17.4)	24 (11.6)	13 (8.7)	0 (0.0)	9 (12.0)	14 (19.4)	12 (9.4)
Other†	11 (14.3)	18 (7.1)	7 (5.2)	7 (7.1)	16 (7.7)	11 (7.3)	2 (8.7)	6 (8.0)	7 (9.7)	10 (7.8)
Marital status‡										
Single	14 (21.5)	33 (15.4)	18 (15.5)	10 (11.4)	26 (14.8)	16 (12.7)	1 (4.4)	10 (15.9)	10 (15.6)	14 (12.7)
Married	51 (78.5)	181 (84.6)	98 (84.5)	78 (88.6)	150 (85.2)	110 (87.3)	22 (95.7)	53 (84.1)	54 (84.4)	96 (87.3)
Education§										
High school or lower	29 (38.2)	78 (31.5)	40 (29.4)	30 (30.9)	56 (27.6)	36 (24.7)	2 (8.3)	20 (26.3)	24 (33.8)	33 (26.6)
Some college	32 (42.1)	97 (39.1)	55 (40.4)	36 (37.1)	86 (42.4)	62 (42.5)	6 (25.0)	30 (39.5)	23 (32.4)	48 (38.7)
Bachelor's or higher	15 (19.7)	73 (29.4)	41 (30.1)	31 (32.0)	61 (30.1)	48 (32.9)	16 (66.7)	26 (34.2)	24 (33.8)	43 (34.7)
Family income‖										
<$30,000	34 (41.5)	82 (32.4)	40 (31.3)	31 (30.7)	65 (31.1)	44 (29.3)	2 (8.7)	22 (31.0)	26 (34.7)	38 (29.2)
$30,000-$50,000	15 (18.3)	38 (15.0)	20 (15.6)	16 (15.8)	30 (14.4)	19 (12.7)	3 (13.0)	12 (16.9)	10 (13.3)	16 (12.3)
>$50,000	33 (40.2)	133 (52.6)	68 (53.1)	54 (53.5)	114 (54.6)	87 (58.0)	18 (78.3)	37 (52.1)	39 (52.0)	76 (58.5)
MD STARnet site¶										
Arizona	18 (20.0)	66 (24.3)	43 (30.3)	27 (25.5)	50 (22.6)	35 (21.9)	9 (36.0)	31 (39.7)	18 (23.1)	31 (22.8)

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Colorado	17 (18.9)	54 (19.9)	31 (21.8)	21 (19.8)	42 (19.0)	33 (20.6)	8 (32.0)	10 (12.8)	16 (20.5)	25 (18.4)
Georgia	21 (23.3)	55 (20.2)	20 (14.1)	20 (18.9)	49 (22.2)	31 (19.4)	2 (8.0)	6 (7.7)	16 (20.5)	26 (19.1)
Iowa	22 (24.4)	48 (17.7)	20 (14.1)	25 (23.6)	33 (14.9)	18 (11.3)	3 (12.0)	13 (16.7)	16 (20.5)	13 (9.6)
New York	12 (13.3)	49 (18.0)	28 (19.7)	13 (12.3)	47 (21.3)	43 (26.9)	3 (12.0)	18 (23.1)	12 (15.4)	41 (30.2)

Abbreviations:

CAM = Complementary and alternative medicine

MD STAR*net* = Muscular Dystrophy Surveillance, Tracking, and Research Network

Data were presented as n (%) and analyzed by the chi-square test or Fisher exact test. Nonusers were the comparison group. Because of missing values, the total for some categories may not match; because of rounding, percentages may not total 100.

*
Significant associations between race and ethnicity and use of any CAM ($P < 0.05$), biologically based practices ($P < 0.05$), mind-body medicine (with or without prayer and/or blessings only) ($P < 0.05$), whole medical systems ($P < 0.05$), and aquatherapy ($P < 0.05$).

†
Including non-Hispanic black, Asian and/or Pacific Islanders, and Native Americans.

‡
Asked only if primary caregiver was the biological parent.

§
Significant associations between education and use of mind-body medicine (excluding prayer and/or blessings only) ($P < 0.05$) and whole medical systems ($P < 0.001$).

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Significant associations between family income and use of mind-body medicine (excluding prayer and/or blessings only) ($P < 0.05$), whole medical systems ($P < 0.01$), and aquatherapy ($P < 0.05$).

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Significant associations between MD STAR*net* site and use of biologically based practices ($P < 0.05$), mind-body medicine (excluding prayer and/or blessings only) ($P < 0.05$), special diet ($P < 0.01$), and aquatherapy ($P < 0.01$).